How A Wellness Mindset Boosts Your Health Transcript

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Introduction and Rosalind Kalbu2019s background

Thank you guys for joining us. let me read your intro. Rosalind Kalb PhD, is a clinical psychologist who specialized in multiple sclerosis care and education for more than 40 years.

After receiving her doctorate from Fordham University in 1977. She began her career in MS at the Albert Einstein College of Medicine, the country's first university based comprehensive care center, and she provided individual group and family psychotherapy and cognitive assessments and remediation, and conducted research on children.

Having a parent with M. S.. She joined the MS Society in 2000, where she created online resources education materials. she has been a valuable member of the MS community.

So, Ros, thank you so much for being, part of the, summit. Pleasure for me. Terry Wahls I was I was, like, being interviewed by you, you know. let's talk a little bit about why, you know, your early work with, psychotherapy and mindset was so revolutionary at the time.

and, can you give us a little bit of that history? Sure. So the reason I mentioned in my bio that this was the first, academically based, comprehensive MS Center was that at the time, this concept of comprehensive care for animals was truly unique.

If people can remember back to the 70s, there were no disease modifying therapies for people with Ms..

Why comprehensive MS care was revolutionary

So comprehensive care meant true attention to people's health, well-being, both physical and emotional. Their symptom management help with relapses. They were having help with employment issues.

They were having, or social challenges. The time wasn't spent on DMT because there weren't any and MRI was in its infancy. So when somebody came to a comprehensive center, it was a wellness approach to helping people live well with MS which is informed my work to this day.

And of course, we sort of, you know, as powerful as the DMT are, it, so disease modifying treatments and they have had a huge impact on disease course.

one of the, things that I worry about is we went through a period where your work on wellness got diminished. and, I don't think it was emphasized, nearly enough.

So let's talk about that. that that concept of wellness, how would you define that? So I think what is important about wellness for people to understand is that it is the whole you.

Right? It is, your physical and emotional well-being, but it's also, your intellectual stimulation and your work, your relationships at home and at work and in your community.

It's your spiritual grounding. and how you feed your body, what, what nutrition you think about, helping you be as healthy as you can be. So different people choose to focus on different aspects of their wellness.

But I think bringing that wellness mindset to Ms. care is the perfect complement. Yeah. Because unless you're healthy and well, you can't, take good enough care of your Ms.

just with a disease modifying therapy. You know, it can be a very helpful tool. The doctors. But, we should be doing our part as well. Yes. Absolutely.

let's talk about what that wellness part is that we could be doing from your perspective. So obviously, as a psychologist, I see emotional well-being as critical to living with a chronic, unpredictable illness.

Whether you're the person who has the disease or a loved one who is supporting, the person with MS This is a tough, tough road, a hurdle, right? And so managing stress, paying attention to the ups and downs of your mood is essential, because our moods can get ahead of us, right?

We can feel out of control of our emotions. We can feel overwhelmed, grief stricken by losses associated with MS or or laid low, laid low by depression.

So that's just one area of wellness that I happen to be passionate about. But the same is felt by nutritionists who care about healthy eating or rehabilitation professionals who care about physical activity.

We're all passionate about all the ways that these wellness interventions can help. Okay. So, we're going to lean into your expertise here a little bit more.

Defining wellness in MS care

so, I certainly have the perception that, diagnosed anxiety, diagnosed major depression, is fairly common for people with M. S. and then if we go beyond, the diagnosis, people who have, symptoms of anxiety, symptoms of low mood, then my interpreter review of the literature is, a majority of people with M. S.

over the course of their disease will develop either anxiety or depression or both. and I certainly know, ever since I was an adolescent, I have struggled with depression.

and fortunately for me, one of the things that I learned is physical activity was very helpful in managing that low mood. you know, so what have you observed?

How common is anxiety and depression and and what kind of techniques are you using? So I think that we know from clinic populations that, depression, significant depression is much more common in people with MS than in the general population.

If you consider people. as you alluded to, who don't necessarily meet the criteria for a major depression, then it's almost universal, right? There are moments of depression, and we know that it's not just because this is a tough disease to have to live with.

We know it's because it's hardwired into the, immune system, the central nervous system. So it is like, another symptom of MS that needs your attention, right?

Just like your bladder and bowel or your walking. and one of the reasons that's so important is that it removes some of the stigma, right? If if people know that it's a symptom of MS and not a symptom of their being weak or wimpy or crazy, they're much more likely to report it to their health care provider and, and get the help they need.

I think we've also learned recently, that there are many options for treating depression and anxiety, which is just as common, if not more. and people can make some choices about how they want their mood managed.

Obviously, we have medications that physicians can prescribe, to help people with depression or anxiety. But we also know that talk therapy, particularly cognitive behavioral therapy.

Let's stop for a moment. Can you explain what cognitive behavioral therapy is? Because, our audience. So cognitive behavioral therapy is a form of psychotherapy that really focuses on the way we think about, what's going on in our lives.

We we frequently bring to life experiences, certain attitudes, certain reactions, certain ideas that may not be in our best interest. We may have learned some things in our past that aren't actually helping us now.

Depression, anxiety, and cognitive behavioral therapy

So in cognitive behavior therapy, the therapist works with you to look at your thoughts about relationships, activities, crises, and examines with you some alternative ways of conceptualizing what's going on or thinking about it, so that by altering your automatic responses to something, maybe you can change the way your mind and body are reacting.

So, let's see if I can paraphrase that. So you're helping me have new insights in terms of the automatic thoughts I might have while they might be flawed and you're helping me see that there are other ways of thinking about that circumstance, that problem that would be more helpful.

Exactly right. And I think what's almost magical about this relationship in, in therapy is that nobody's saying, oh, you're thinking is wrong. Think this way.

Instead it's say, a general X, but the general and gentle exploration of the way you think about things and whether they're thinking about them differently might feel better to you.

Might serve you better. But it's a joint exploration and it's, it's amazing. I think that's important for a brain who's listening to hear that. It's a joint exploration of new responses that might serve you better.

Okay. So what what are the steps. so I, I'm newly diagnosed with that mess. I know that I am aware that I have anxiety, low mood symptoms. and I'm fearful of my future.

What are the steps that you would encourage me to take? as I'm, we're hoping to get them further with this wellness journey. So I'm glad you asked, because it gives me a chance to talk about the third leg of the treatment stool.

Some people say, give me a pill. I want to feel better. Some people say, I don't want to take another pill for anything. I want to talk to a therapist.

I'm much more comfortable with that. And some people say this whole therapy thing is hard. I I'm not comfortable with that. But I'm I'm comfortable with the idea of being more active, being more physical, being more out there.

Okay, so here's what we now know about the treatment of depression and anxiety. Exercise works. Talk therapy works. Medication works. In my mind it is a three legged stool and they all work best together because medicine only deals with what's actually going on in the brain.

While the talk therapy helps you work through challenges, conflicts, feelings, and exercise has now been shown, to relieve mood issues. Yeah, so people can put together a package that works for them.

You know, I'm reading this wonderful book, an extended mind. I just read the chapter on movement and how as we move, it activates other parts of our bodies, and activates our brain in different ways, improving our alertness, our, thinking ability.

And, of course, as, Roz and I chatted right now, it does improve our mood. So, everyone is listening. I want you to be sure and move. Fidgeting in your chairs.

Find that low intensity movement. That's fine. Yeah. Going for a walk? Moderate intensity. That's good. If you're still well enough, you can do high intensity.

That is great too. But whatever movement you can do with it would be very helpful. you know, one thing I think you said, how how would you go about starting all this?

I think it really starts with examining yourself. How do I feel? Is my mood where I needed to be? Am I hearing from family or friends that maybe my mood is off and then it's bringing to the attention of your health care team, right?

Yeah. They can't. They can't read your mind. They can't read your feelings. You need to step up and bring it up and then ask about these different legs of the stool that the team might help you with.

You know, and I think you, touched on that. It's really important to check in with your family because it's it's hard to have, the self-awareness of our mood.

I may be aware of a sense of anxiety and panic. I may be aware of a low mood, but more often in my patients, I would ask them, how are you getting along with, your family?

Are you really crabby, or are they annoying you? Are they making you angry because that irritability, to me, is a big warning sign that we're spiraling into depression or anxiety.

Exercise, mood, and the three-part treatment approach

And I think the word I use with people a lot is prickly. If your family members are telling you you're like a prickly cactus, you're overreactive, you're hyper.

in your responses to things, quick off the trigger, quick off the mark. That's a sign, right? That's something to pay attention to, because we know that irritability is a common accompaniment of, significant mood changes.

is there a, similar term for anxiety that you could help people recognize? that they're getting anxious? I think in today's world, people are kind of chronically anxious.

Terri. I think that's kind of the state we are in at the moment. But what I when I ask people to think about is, is your sleep disrupted? Are your relationships, your activities disrupted by worries and concerns and panicky feelings, that are above the norm.

Right. We know life is hard and we know that things are stressful right now, but if you're ruminating and not sleeping and not reaching solutions, just going over and over these scary thoughts in your mind, that's a red flag that, yeah, that you could use some help in. So if, it's your loved one that's having Ms..

And were recognizing that I'm concerned that my loved one is having more anxiety or they're more prickly. what suggestions you have for the family, or the adult support person.

So my general recommendation for couples and families, and this has been more true, actually, since the pandemic when we started this in our household, we ask each other how we're doing.

how are you feeling? What's on your mind today? Is there anything you and I need to talk about? to get to a better place? And. And I think it goes both ways, because we know that care partners of people with Ms.

also have higher rates of depression and anxiety. And so this mutual check in is a it is a partnership. and the partnership works when people are honest and upfront with each other.

and get some of those worries out on the table because worries are easier to handle in pairs or in family gatherings. It's certainly can become very destructive if we don't talk about it.

Right. that that can be, very, very hard, in isolating, in loneliness. So let's talk a little bit about loneliness. I see that as a, a concern that I have for people with Ms..

they're not wanting to acknowledge, that they have their illness. and perhaps are feeling more and more isolated. do you have any thoughts about how to prevent that?

So I want to back it up a step and talk a little bit about grief, because I think grief for many people sets in motion a lot of these other mood changes and social changes that we're talking about.

I think that grieving is part and parcel of living with a chronic, unpredictable illness that has a way of taking important things away may change your abilities.

It may change your relationships. It may isolate you. in some ways. And there's this sense that you're grieving alone, that nobody can quite get it. or they can't see what's going on inside your body.

You may look fine to them, but, you know, you've maybe lost some cognitive abilities or, you know that you can't do your job at work as well, or you can't do your hobbies as well, and you are sad and you're grieving and others don't get it.

Recognizing mood changes and supporting loved ones

So sometimes the isolation I think comes from this feeling that others just can't understand. Right? That's part of it. Sometimes the loneliness comes because other people don't know what to say to you.

they don't know what questions to ask their Mr. side by this illness that is primarily invisible to them. Yes. Right. And so they may back off because they're so afraid of saying the wrong thing.

They don't say anything. And then gradually, ones world, when social world can begin to shrink or shrink, and then when abilities change. You may stop doing some things or going places that you used to do, and then your physical world begins to shrink and there's nothing lonelier than feeling that you're in this gradually shrinking, shrinking.

Spot. With fewer and fewer people who understand or who are part of that with you? and, and unfortunately, I think it's up to people with Ms. to break through the loneliness, to reach out, to engage, to try new things.

This is where the rehab team is so fabulous, because we as mental health professionals can help you with the feelings. But the rehab team can help help you figure out how to do the things you want to do.

You want to be doing, and keep active and get out in the world. and those are part of the comprehensive care strategies for helping with that loneliness.

And, thank you, Ross. This this has just been wonderful. And everyone who's listening, thank you so much for joining us today, and I hope you found our conversation insightful and engaging.

And if you're a summit purchaser, stay right here because we're about to dive even deeper into this wonderful conversation. If you're not, click on the button below to or to the side to get access to a world of information.

Get ready to reclaim your health. Know if you're watching this. Thank you for being a valuable member of our community. Let's dive right in. So I, think it's so important that we prevent that isolation, that loneliness, that, as you were talking, ever shrinking sphere, with which I operate, you know, and I think about how small my world got, I got so I couldn't sit up anymore, you know, I couldn't go out to eat.

it was really hard to drive, very far. I couldn't go to movies. and so, you know, it was getting smaller and smaller. How do we help people avoid that?

again, I, I think it starts with asking people to check in with themselves. How am I doing? Am I seeing the people I want to see? Am I engaging in activities?

I am in my out in the world. We real, honest self-assessment. And one of the ways that we have been doing this to can do Ms. programs, which is the organization that I, work with, is something called a pie exercise.

And it's fascinating because we ask an individual or both people in a, in a couple. To draw a circle on a piece of paper, like it's a pie and, and then draw a segment that indicates how big a slice of their pie Ms. is.

And if they're doing it with a partner, don't share it. Don't look, do it individually on your own. And then our conversation is around, okay, how's that slice of your pie?

Is it too big or is it taking up more time and attention and energy and space than you want it to in your life? Is it about the right size in your life, or is it too small?

Are you not dealing with the changes or the, symptoms that you have in an effective way? In fact, you're just sort of trying to block it all out and charge ahead without doing what you need to do to take care of yourself.

It prompts some really good self-examination. And in couples, it prompts wonderful conversations about the balance in their partnership. Whether Ms. is getting more attention than it needs to or not enough.

Yeah, yeah. And I think that's the starting point, Terry.

Loneliness, grief, and shrinking social worlds

I think if you start to think about your life, pie and Ms. is all over it, right. It's taken up every bit of your energy and time. Then the question which the Ms.

Care team can help you with is, okay, what are those things that have impaired your your activities in the world? Is it your mood? Maybe it's your physical limitations.

You can't even get out of your house. Perhaps it's that you're embarrassed to be around other people, or they're uncomfortable being around you because nobody knows what's to say.

And so it's your social life that's shrunk. But as members of the team, we can explore that which, again, is what we do. It can do that mass, because then people can choose their own path to broadening their world, feeling better, enhancing their wellness.

And then it's our job to help them identify tools and strategies to get where they want to be in their life. So let's talk a little about Can Do. This is such a wonderful resource.

I've gotten to participate in some of your programing. and so I, really enjoyed that. What is it? and how could people access that? So it's, it's a health and wellness organization based in Colorado that was actually started by Jimmy Hugo, who was an Olympic skier who was diagnosed with them as, shortly after winning an Olympic medal in downhill skiing.

And at the time, he was told to go home and rest and not exercise. And he tried that for a few months and got so depressed he couldn't stand it and said, this isn't the way I'm going to manage my mess.

I need to manage it with exercise and activity and how I eat, and I just, I'm an athlete. I can't, I can't sit around and not doing anything, do anything.

So he started a health and wellness program for people living with Ms. to help them focus on what they can do, as opposed to always focusing on what they can't do.

And at this point, I think we're the perfect adjunct to the DMT, to the the wonderful, wonderful medical interventions that are now possible for people with Ms.

but that drown out wellness because there's not enough time in a doctor's appointment to talk about things. So our health and wellness programs, which are now mostly virtual and can be accessed in the can do website, which is can do hyphen Ms.

dot org, are really based around a coaching model. We don't we don't talk at people very much, although we have monthly webinars, which are probably our most didactic, materials, although they're interactive too.

But the rest of our programs are all focused around coaching, where people get some didactic information from a multidisciplinary team, always multidisciplinary.

But then break into small group sessions facilitated by health care professionals where they learn and problem solve together, not just with the leaders or the health care professionals, but learning from each other.

You know, in my experience, when, I was at the VA, we had the Therapeutic Livestock Clinic. What was incredibly interesting to me was the peer to peer conversations.

The more senior folks have been in, with the newbies coming in that month, they were. That was magical. It was so much easier for the newbies to learn from other peers about how they could improve their diet and their self-care.

much more so than from, the dieticians or the physical therapists. so, yes. So everyone who's listening, the fact that can do has this peer to peer interaction.

That is where the magic really happens. And I think that that's exactly right, Terry.

Using the pie exercise to assess MSu2019s impact

And I think our mantra is sort of that you provide information, you offer opportunities for connection. And then people leave with, ideas for how to take steps forward.

So active information, connection and activation so that people, leave each program with a step or two they want to take. If they can do and then do they have the ability to have, check ins with the people that they've met?

yes. So in all of our multi-day programs, people can opt in to have their contact information shared. So most people do opt in, but you don't have to.

And after the multi-day program, anybody who has opted in is then sent a list of the contact information of people who were in their group. And what is the multi-day program like?

What what what is what happens then? So, right now we are focusing on, two day take charge programs which start the night before where people get to know each other.

there's a panel discussion, there's some breakout conversations, on different topics, whatever. And then the next day is a series of workshops. all day long.

And each workshop is facilitated by a team of health care providers. But people cycle through generally three workshops. in addition, there's some physical activity built into the day so that people aren't sitting the whole day.

And then the day ends with a, a group discussion for people with Ms. and a separate group discussion for care partners. because we always want to make sure the care partners get some time and attention since they're living with them as two.

and every one of our programs has that option for care partners to have their own time. And now we have, community programs where we're partnering with, comprehensive EMS centers around the country to, offer full day programs for people in the community to now that the pandemic is hopefully behind us, where people can get together and do this kind of coaching work in person.

and yeah, so this is all virtual, what you need is a smartphone or a, computer, or you can go to your library if you don't have your own, computer, to register.

And I assume that these are a variety of, times of day. yes. they vary by, day of the week and by time of the day to try to accommodate those two day programs, focus on, specific groups, like it might be a program on aging with Ms..

Can Do MS programs and peer coaching

It might be a program for people more recently diagnosed, we have, a take charge for the African-American community. and then we will, I think, in the next couple of years, get back to having our even longer program, which was a two and a half day, program, that really allowed for even greater deep dive into the the topics that are of most interest to people.

Everything is free. there's no charge for any of these programs. The only thing that is consistent among our programing is Webinar Wednesdays. the second is that every Wednesday, Wednesday, the second Wednesday of every month is Webinar Wednesday, and people can register just once, and then they're registered for everything.

They can come to any of the programs that they that they want. And we have coaching programs, multi week coaching on a variety of topics that people can join us for weeks in a row to tackle nutrition or fatigue or cognitive issues.

Every year of the coaching series, a different. Well, I'm going to hope that your nutrition folks are praising the radical idea of eating vegetables. Absolutely.

We we are big on veggies now. Vegetables are, you know, and a few berries. It's a work on things to add. and I think that's in general much easier for patients and families if we focus on what to add, whether it's, a prayer or gratitude before our meals or a walk with around the block with our kids or a little backyard sit outside, just sitting outside with a cup of tea, just adding some wellness behavior.

it sounds good. I'm going to come to your house. Yes. Those things, yes. That that would be very lovely. We have, a row of, blackberries. Thornless in a row of black raspberries, thornless that we planted because I am hoping, that, in a couple of years, we'll have a little helper helping me pick those, because my, son and his wife were expecting, a child.

that will hopefully be happening sometime this spring. So congratulations. That is very news, Terry. I am. Very excited about that. Grandparent. I am very, very excited about that.

so I've been looking at our garden, just visualizing getting to share the gardening, with, a little person again. Who doesn't eat every berry that is picked.

Well, you know, if they eat every berry that they'll they'll just keep them busy. It'll be good. A good busy. That's true, but there won't be any for your breakfast.

Well, so, what do you think is the, one, key message that you would like to have all of the listeners, take from our conversation today, right. Take your wellness mindset to the neurologist.

We hope that neurologists have wellness mindsets, too, but they don't actually have time for it. So it's your job to bring your wellness goals in, say this is an important part of my life.

I want to get it to a better place than it is right now. What resources can you point me to keep in mind that can do? Ms. can help you, and if your doctor doesn't know about can do Ms.

passed the word to him or her as well. But wellness is is your absolute best way to live a full and comfortable life with MS I'd like to, build on that a little bit, because they are neurologists are, pressed for time and there aren't enough neurologists to go around.

Most of you should also have a primary care physician, nurse practitioner, pay, and they should be very comfortable at you supporting your wellness mindset.

You can come talk to them about concerns you have, about your mood, about your mobility.

Key wellness takeaways and finding Can Do MS

They took can support getting, some counseling, some nutrition, guns, that you may be eligible, to get a referral, in your insurance plan for a registered dietitian visit or a visit to physical therapy, occupational therapy, or a clinical psychologist, to help you with, talk therapy.

So, unfortunately, we know that people with M. S. sometimes see neurologists and quit seeing their primary care. Yes. I want to put a word. Keep seeing your primary care because they can help, too.

Because you're a neurologist, maybe too busy to help your wellness goals, but your primary care person should be very, very supportive. And the neurologists that I know are the first to say, look, I'm not a primary care physician.

Your other areas of health are not my primary expertise. You need the care of a PCP. In addition to what you get from me. So thank you for adding that, Terry.

I think I think it's an important reminder people need both of those. Yes, health care providers. You know, and when I'm seeing people, for their MS care, as the, primary care person who's into functional medicine, integrative medicine, we, of course, are working closely with the neurology team.

I think everyone with MS will benefit greatly from great neurology care and great primary care. And, you know, great wellness should be supported by both sets of teams.

But you need to advocate for yourself because they may not be focusing on those things. So you need to make sure that your providers are focusing where you need them to focus.

Absolutely. And that goes for the primary care person too. You tell them that you want to be advocating for your wellness. Yes. Ros, this has been wonderful.

Always love our conversations. And thank you so very much. what And one final thing where can people find can do MS www.cando-ms.org www.cando-ms.org Please come find us.

We welcome you to our community. Thank you so much. Thank you.